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SIZE AND COMPOSITION OF THE KIN FAMILY AND CAREGIVING FAMILY OF SPOUSE AND ADULT CHILD PRIMARY CAREGIVERS OF RELATIVES WITH ALZHEIMER'S DISEASE

BY

NANCY DAVIS-PATSULA

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A THESIS
SUBMITTED TO THE FACULTY OF GRADUATE STUDIES AND RESEARCH
IN PARTIAL FULFILMENT OF THE REQUIREMENTS FOR THE
DEGREE OF MASTER OF SCIENCE

IN

FAMILY LIFE EDUCATION

DEPARTMENT OF HUMAN ECOLOGY

EDMONTON, ALBERTA

FALL, 1995

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Degree: Master of Science

Year this Degree Granted: 1995

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The undersigned certify that they have read, and recommend to the Faculty of Graduate Studies and Research for acceptance, a thesis entitled Size and Composition of the Kin Family and Caregiving Family of Spouse and Adult Child Primary Caregivers of Relatives with Alzheimer's Disease submitted by Nancy Davis-Patsula in partial fulfilment of the requirements for the degree of Master of Science in Family Life Education.

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Dr. Sharon Warren

Dr. Brenda Munro

Abstract

As the population of Canada continues to age and we are faced with increased cut-backs to the health system, care of the frail elderly will be of increasing concern. These changes have significant implications for the elderly as well as their families. The number of elderly persons who may require care will continue to increase and the expectation that families will assume this responsibility will prevail. Despite widespread acceptance for the notion of family caregiving, there is a lack of understanding regarding who is involved in this process. Most researchers have studied the involvement of one family member, referred to as the primary caregiver. Although in recent years attention has been shifted to the role of other kin family members in the caregiving process, little is known about the configuration of the helping networks and which factors affect who becomes involved in the process of caregiving.

The focus of this research was on the composition of caregiving families. The major assumption underlying this study was that the caregiving family is socially constructed. This construction takes place within a societal context and is influenced by a number of variables. Some of those variables are highlighted in the hierarchy of obligation proposed by Qureshi and Walker (1989). The purpose of this study was to extend their hierarchy to understand the selection of secondary caregivers to relatives with Alzheimer's disease. The primary research question addressed in this study was what characteristics of kin family members describe who becomes involved in provision of care to relatives with Alzheimer's disease.

Data were drawn from the first phase of a 5 year longitudinal study of caregivers of relatives with Alzheimer's disease. Data from 104 spouse and adult child caregivers was taken in order to address the present research questions. Information was gathered through face-to-face interviews with the primary caregivers. Data on the characteristics of the ill relative, primary caregiver and kin family in addition to help provided by kin family members to the primary caregiver were the focus.

Findings illustrated that several characteristics of the ill relative, primary caregiver and kin family members are helpful in determining who becomes involved in provision of secondary care. Possible explanations to account for the research findings were presented, the limitations inherent in this research as well as implications and direction for future research were presented.

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Chapter 1

Statement of the Problem

The belief that the family is central in provision of care to the elderly is well established in the caregiving literature (Aronson, 1992; Dwyer & Coward, 1992). Family care to the elderly is viewed as both efficient and cost effective as well as superior to public care (Hooyman, 1992). Many researchers have focused on family caregiving and the frail elderly. Implicit in this body of research are the assumptions that families should provide care to their elderly members and that they do assume the major burden of care (Bliezner & Alley, 1990; Finch & Mason, 1990; Guberman, Maheu & Maille, 1992). In fact, researchers have shown that families institutionalize their elderly only when their emotional, physical, and financial resources are exhausted (Allan, 1988; Archbold, 1983; Brody, 1985; Cohen & Eisdorfer, 1988; Lebowitz, 1985; Ory et al., 1985; Pruncho, 1991; Shanas, 1979; Zarit, Reever, & Bach-Peterson, 1980).

Although the research literature refers to family caregiving, exactly which family members are involved in providing elder care remains unclear. Most researchers have limited their analyses to how one family member, often called the primary caregiver, provides assistance to a frail elder (Barer & Johnson, 1990; Cohen & Eisdorfer, 1988; Fittings, Rabins, Lucas, & Eastman, 1986; Stone, Cafferata, & Sangl, 1987; Zarit et al., 1980). While a good deal is known about the primary caregiver's role in the provision of care to the elderly, there is less

information about whether she provides care alone or along with other kin family members. Recently, researchers have begun to explore the role of other kin family members, often called secondary caregivers, in the provision of care to frail elders (Brody, Hoffman, Kleban, & Schoonover, 1989; Matthews & Rosner, 1988; Stephen & Christianson, 1986; Tennstedt, McKinlay, & Sullivan, 1989). Although these studies suggest that primary caregivers may receive assistance from other kin family members, much of the current research tells us little about which kin family members are part of the caregiving family (Barer & Johnson, 1990).

In order to assess family caregiving, it is necessary to examine the involvement of other kin family members in addition to the primary caregiver. Understanding which family members are involved is essential given that policies are formulated on the assumption that families provide care. Researchers have argued that the family can be imperiled when it is viewed as a solution to societal problems (Dwyer & Coward, 1992). Yet, many policy makers and researchers continue to promote the notion of family caregiving and to formulate policies based on this assumption.

Researchers have focused on the involvement of the primary caregiver in terms of who is most likely to assume this primary role in provision of care to the elderly. In particular, Qureshi and Walker (1989) proposed a hierarchy of obligation to predict involvement of kin family members as primary caregivers.

They found that characteristics of the elder, primary caregiver and kin family members influenced provision of informal care to the elderly. Factors such as gender of kin family member, geographic proximity and kinship relationship to the elder were shown to predict who became identified as a primary caregiver to a frail elder.

Less attention has been directed at the likelihood of other kin family members becoming involved in secondary care to the frail elderly. This group of individuals is of primary interest in this study. The primary focus of this study was to determine whether preference for secondary caregivers follows the hierarchy of obligation proposed by Qureshi and Walker (1989). That is, this study examined the impact of the characteristics of primary caregiver, ill relative and kin family members on involvement in the provision of secondary care to relatives with Alzheimer's disease (AD). The main research question addressed in this study was:

Who are the members of the caregiving family?

Chapter 2

Theoretical Framework

The purpose of this chapter is to outline the theoretical framework and underlying assumptions that guided the present research. Since the focus of this study was on the structure of caregiving families, the basic theory guiding this study was social constructivism. The major underlying assumption of this research was that the caregiving family is socially constructed.

Theorists have argued that the structure and boundaries of families are fluid. That is, families are socially constructed in terms of who are and are not considered members. If a group of kin is asked 'who do you consider to be members of your family?', each kin family member may provide a different response. For instance, a woman may conceive of her family as including her husband and two children. Her husband, on the other hand, may regard his wife, two children and his parents as members of his family. Kin family members, therefore, may differ in terms of whom they see as inside and outside of their family.

The underlying belief of social constructivism is that perceptions of reality are created through selecting, ordering and organizing information. Consequently, knowledge, truth, power and social relations are created as opposed to discovered (Flax, 1987; Hare-Mustin, 1990, cited in Barber & Allen, 1992). Accordingly,

individuals are seen as actively involved in the process of creating their own systems of meaning.

The Social Construction of the Family

How has the family been traditionally constructed? This question has been the subject of much debate and controversy over the years. At a theoretical level, it is acknowledged that there are many constructions of the family (Eichler, 1983). Among researchers, there is little agreement with respect what constitutes a family, in general and in particular, who comprises the caregiving family (Keating, Kerr, Warren, Grace & Wertenberger, 1994).

Though the family is seen by constructionists as being constructed in a variety of ways over time and across people, Eichler (1983) argues that there has been a tendency to overlook the broad and diverse nature of the family and to treat families as having a single structure. She called this approach the monolithic bias. This bias is evident in the contemporary definition of the family proposed by White (p.7, 1991): "A family is an intergenerational social group organized and governed by social norms regarding descent, affinity and the nurturant socialization of the young." Within this construction, reproduction, socialization and nurturance are regarded as central functions of families. Within the context of the family, women have been given responsibility for nurturing and caring for others especially the young, old, ill and those in intimate relations with them (Houston, 1989). This

construction of membership in families and responsibilities for caregiving is well-established (Walker, 1991) and has been virtually unchallenged.

It has been suggested that some policy makers construct families in a particular way for specific purposes (Eichler, 1983). For example, in the past, the welfare system did not consider a man and women who reside together as a couple. As a result, a woman was not entitled to receive social assistance benefits if she resided with a man. Constructing families in a specific manner has had consequences not only at the individual level but also at the level of policy. As Eichler (1983) points out, when family policy is directed toward the betterment and protection of a particular type of family, it works against the other types of families that do not conform to the prescribed structure (Eichler, 1983). In the previous example, women were financially penalized if they did not conform to the traditional family structure which included a married couple.

The Social Construction of the Caregiving Family

Like families in general, caregiving families are constructed at the societal and individual levels. For example, Walker (1991) argues that the state plays a prominent role in promoting the primacy of family care and in maintaining the dominant role of the family. In particular, female kin are seen as central to the provision of care to the elderly. This ideology, called familism, suggests the social construction of a traditional caring relationship with women assuming primary

responsibility for provision of care to the elderly. Within this construction, beliefs regarding responsibility for care of the young, old and ill relatives are internalized. Women's involvement in provision of care to the elderly is regarded as a natural extension of their other caregiving tasks.

Other theorists also believe that the state plays a primary role in promoting family care to the elderly. For instance, Medjuck, O'Brien and Tozet (1992) believe that Canadian social policies reflect and reinforce the ideology of familism by assuming that family is necessary for care of older relatives and within it, females are the most appropriate carers.

The different scripts of men and women regarding responsibilities for care to the elderly are formulated and reinforced at a societal level. It has been argued that the social construction of caregiving is gendered (Hare-Mustin & Marecek, 1990, cited in Barber & Allen, 1992) and that the social construction of gendered roles in caregiving is the major determinant of the inequities in family roles such as elder care (Hooyman, 1992). It is in the interest of the political structure to polarize men and women and allocate social roles according to gender. Thus, social and political subordination may be a more appropriate explanation for why women are identified more often as part of the caregiving family.

Post modern feminists argue that we must move beyond merely accepting normative beliefs and expectations about family caregiving and move toward

understanding their roots and how they function for society at large (Barber & Allen, 1992). Through the process of deconstruction, post modern feminists challenge traditional beliefs and argue in favour of re-evaluating existing social relations. For instance, this process would involve examining and re-evaluating the belief that women should care not only in terms of its' roots but also the purposes served by perpetuating this belief at both an individual and societal levels.

Keating et al. (1994) have recently addressed the issue of who comprises the caregiving family. There is little agreement regarding the definition of the caregiving family. They argued that there has been a tradition within the caregiving literature to regard the kin family and caregiving family similarly. That is, if kin family members exist, they are presumed to be involved in the provision of care to the elderly. The authors proposed that the assumption that the kin family and caregiving family are equivalent should be rejected based on literature which illustrates that not all close kin provide help. Keating et al. (1994) further challenged this assumption, suggesting that like kin families, caregiving families are socially constructed. This social construction occurs such that kin are included and excluded based on the preferences of the primary caregiver. Therefore, rather than talking about one construction, there may be many constructions of caregiving families.

In an effort to clarify the concept of the caregiving family, Keating et al. (1994) proposed that the caregiving family consists of two elements. These two parts included: "those who provide help and those who are potential sources of help to the primary caregiver" (Keating et al., 1994, p.276). Kin family refers to those individuals identified by an individual as part of his or her family. The theorists further argued that these two parts provide different insights into the nature of family care including what people do in addition to what people are expected to do in relation to care of the elderly.

Social Construction by Individual Family Members

How is the caregiving family constructed by individual family members? Qureshi and Walker (1989) proposed a theoretical model of decision making rules that predicts order of preference of principal helpers or primary caregivers from the perspective of the elder. They argued that decisions about who should provide care to the elderly are based on rules that derive from stereotyped beliefs about the debts owed by children to their parents and expectations about appropriate gender roles. Their model was constructed on the basis of a traditional normative preference structure which rules suggest that "close relatives are preferred to more distant ones, any relative is preferred to a non-relative and female relatives are preferred to male relatives" (Walker, 1991, p.98). Qureshi and Walker (1989) argued that their hierarchical model reflects people's beliefs about what is right to

do. The normative rules which form the basis of the hierarchy appear to concur with societal expectations that the family should provide care to the elderly and in particular, women.

Initially, their hierarchical decision model was based solely on kinship relationship to the elder. This hierarchy of preference gave priority to available relatives and included the following:

1. spouse
2. daughter
3. daughter-in-law
4. son
5. other relative
6. non-relative

Their initial model only took into account either the existence or non-existence of relatives. Among those situations in which the decisions for selection of primary helpers did not follow the hierarchy, the model was altered if a relative resided in the same household. Relatives residing in a joint household appeared to be preferred to those living outside it.

In recognizing that normative rules were modified in practice by other variables such as geographic proximity, their model was revised accordingly. Walker (1991) argued that, in practice, decisions about who provides care operate

in accordance with the hierarchy of obligation with the exception that the ill health of potential helpers overrules their obligation to become involved in caregiving. However, insufficient data were available on the health status of relatives to allow this variable to be part of the model. Their final hierarchical model for the selection of primary caregivers was as follows:

1. spouse
2. relative residing in joint household
3. daughter
4. daughter-in-law
5. son
6. other relative (living locally)
7. non-relative

Qureshi and Walker (1989) employed the hierarchy of obligation to predict the selection of primary caregivers. Most of the research completed to date has focussed on the role of the primary caregiver in provision of care to the frail elderly. In contrast, researchers have not systematically examined the composition of the caregiving family (Keating et al., 1994). Policy makers and practitioners continue to promote the efficacy and superiority of family caregiving without an understanding of the nature of family support. The hierarchy of obligation could be applied to account for the selection of secondary caregivers. In turn, this could

provide us with a better understanding of how the caregiving family is socially constructed and its configuration. This information is essential in order to make informed decisions at both the levels of policy and practice.

Summary

The social construction of the caregiving family is a combination of individuals' preferences among available helpers and beliefs about who should care. Decisions about preference for helpers are believed to occur in a hierarchical manner and to be affected by gender, geographic proximity, marital status and kinship relationship. The social construction of caregiving families does not occur in a vacuum; rather, caring is a social relationship that must be considered in the context of political realities, material conditions and social structures of the world (Hoaglund, 1991, cited in Barber & Allen, 1992). As a society, we are socialized to believe that caregiving is a natural extension of the female role. Women are expected to place their needs aside and care for others. A post modern feminist perspective suggests that caregiving must be understood within a societal context. Further, one must challenge traditional beliefs and expectations about men and women and consider the consequences of these prevailing beliefs at an individual and societal level. Ultimately, these beliefs and expectations about care to the elderly which influence the social construction of the caregiving family serve to function the interests of the overall political structure.

The hierarchy of obligation proposed by Qureshi and Walker (1989) could be utilized to assist us in understanding how the caregiving family is socially constructed and to determine who are members of the caregiving family. Only with a better understanding regarding the construction of caregiving families and by deconstructing the beliefs and expectations regarding care to the elderly, can we move toward a more equitable situation and better meet the needs of the elderly and their families.

Chapter 3

Literature Review

Despite common reference to the term family caregiving, researchers remain uncertain about who is involved in the caregiving process. Most of the researchers who have studied family caregiving have limited their analyses to the involvement of one family member, often referred to as the primary caregiver. This body of research is important as the choice of the primary caregiver influences the selection of other family members. The first step in reviewing the literature is, therefore, to examine what is known about who is likely to become a primary caregiver. The following review of the literature identifies pertinent characteristics of the primary caregiver, kin family members and ill relative that have been shown to influence involvement in caregiving.

I. Involvement of Kin Family Members as Primary Caregivers

The hierarchy of obligation (Qureshi & Walker, 1989) predicts that spouses are most likely to assume the role of primary caregiver. Other researchers have also found that the main source of support to the elderly is the husband or wife of the care recipient (Chappell, 1991; Fittings et al., 1986; Miller & Cafasso, 1992; Miller & McFall, 1991; Ory et al., 1985; Shanas, 1979; Stoller & Earl, 1983; Stoller, 1983; Stone et al., 1987). When a spouse is unavailable, adult children are most likely to assume the role of primary caregiver.

Consistent with the hierarchy of obligation, the caregiving literature shows strong support for the proposition that most primary caregivers are female (Baille, Norbeck & Barnes, 1988; Birkel & Jones, 1989; Finley, 1989; Fittings et al., 1986; Johnson & Catalano, 1983; Montgomery, Gonyea & Hooyman, 1985; Pruncho & Resch, 1989; Silverstein & Litwak, 1993; Stoller, 1983; Stone et al., 1987; Strawbridge & Wallhagen, 1991; Tennstedt, Crawford & Mckinlay, 1993; Zarit et al., 1980). This finding lends support to the prevailing assumption that caregiving is deemed to be women's work (Medjuck et al., 1992). This finding has been found to hold across kinship relationship such that wives, daughters and sisters are more likely than husbands, sons, and brothers to provide assistance to the elderly (Barusch & Spaid, 1989; Coward & Dwyer, 1990; Dwyer & Coward, 1991; Matthews & Rosner, 1988; Tennstedt et al., 1989).

Geographic proximity also influences the selection of primary caregivers. Researchers have found that geographic proximity significantly increased the probability that adult children would be named as part of their parents' helping network (Stoller, Forster, & Duniho, 1992). Children living within one hour travel time from the elder were more likely to be named as primary caregiver. Availability of proximate sons increased the likelihood that a son would be identified as a primary caregiver especially when there were few proximate daughters available (Stoller et al., 1992) This finding may be a function of the type of assistance

required. Parents requiring occasional help demonstrated no preference for a son or daughter as their primary caregiver. In contrast, parents who required regular assistance were more likely to name their daughters as primary caregiver. Other researchers have found similar results. For example, Silverstein and Litwak (1993) found that older parents who lived closer to their primary children were more likely to receive household and social-emotional support (Silverstein & Litwak, 1993). Thus, geographic proximity not only affects who is named as part of the caregiving family but also influences the type of assistance provided to the elder.

Not surprisingly, researchers have also found that living arrangement influences who provides primary care to the elderly. Among elders living alone or with non-spousal others, daughters and sons were most likely to be identified as providing instrumental assistance than were spouses, siblings, grandchildren, other relatives and friends (Chappell, 1991). Among elders living alone, daughters were most likely to provide emotional support followed by friends, sons, siblings and other relatives. Those elders residing with non-spousal others were found to receive emotional support from their daughters followed by sons, siblings, friends and other relatives. Chappell (1991) found that when available, the spouse was the most likely source of support and adult children were the next line of support when the spouse was unavailable to provide assistance.

II. Involvement of Kin Family Members in Provision of Secondary Care

The focus on primary caregivers has resulted in a lack of clarity concerning whether the primary caregiver provides care alone or is embedded in a network of helping kin. To address this gap, researchers have begun to examine the role of other kin family members, often referred to as secondary caregivers, in the provision of care to the elderly. Secondary caregivers are those people who provide informal assistance to an elder beyond the care provided by the primary caregiver (Keating et al., 1994). Secondary caregivers may provide either direct care to the care recipient or indirect care to the primary caregiver. This includes both instrumental and emotional support.

Researchers have found that care of the elderly was shared rather than the sole responsibility of the primary caregiver (Matthew & Rosier, 1988; Stephens & Christianson, 1986). Contrary to the myth of alienation, there is some evidence to suggest that most frail elders received assistance from one or more informal helpers, typically from other kin family members (Matthews & Rosner, 1988; Miller & McFall, 1991; Pruncho, 1990; Stephens & Christianson, 1986; Tennstedt et al., 1989). For instance, Pruncho (1990) found that spouse caregivers received at least some assistance caring for their impaired spouses, with a mean of 1.4 helpers.

While there is evidence to suggest that caregiving is a shared responsibility,

little is known about exactly which kin family members are involved in this process. Like research on primary caregivers, preference for secondary caregivers appears to operate according to the hierarchy of obligation. The hierarchy of obligation predicts that spouses are most likely to be involved in caregiving followed by adult children. Among spouse caregivers, given that spouses are most likely to be involved as primary caregivers, it is not surprising that their involvement as secondary caregivers is limited. Contrary to the hierarchy of obligation, the involvement of spouses as secondary caregivers among spouse caregivers would be expected to be limited. Given that the ill relative is their spouse, one would not expect them to be involved in provision of care as they are the focus of care. When the primary caregiver is an adult child, however, spouses would be expected to play an active role in providing help. Despite the difference between these two caregiver groups with regard to the involvement of spouses, there is some evidence to suggest that the hierarchy of obligation holds such that daughters are more likely to be involved as secondary caregivers than sons or daughter-in-laws, siblings, grandchildren, other relatives or non-relatives (Stone et al., 1987). This was also evident in a study conducted by Stoller (1983) who found that nearly half of the helpers identified by elders were adult children.

Preference for female relatives over male relatives is also evident in the research on secondary caregivers. Some researchers have found that the majority

of secondary caregivers were women (Stoller, 1990). This finding, however, is not conclusive, as other researchers have found conflicting evidence to suggest either greater or equal involvement of men as secondary caregivers. A study conducted by Stone et al. (1987) revealed that men were more likely to be named as secondary caregivers. In particular, sons (52.2%) have been found to be more likely than daughters (29.2%) to be named as secondary caregivers (Stone et al., 1987). Stoller (1983) found that women comprised 24.7% and men 22.3% of the secondary caregivers. In another study, she found that men comprised forty-one percent of the helpers identified (Stoller, 1990). Although there is evidence to suggest that men and women may be more equally involved as secondary caregivers, this relationship appears to be mitigated by type of assistance required. For example, among elders requiring routine assistance, men were found to be less likely than women to help with cooking, light chores, and laundry (Stoller, 1990). The caregiving literature suggests that men tend to provide intermittent help and assist with gender specific tasks such as financial assistance.

The relationship between gender and involvement in caregiving therefore appears to be moderated by the type of assistance required. Traditional division of labour is evident in the literature focusing on secondary caregivers. Researchers have found that the amount and type of assistance provided to the elderly varies according to gender. When daughters were secondary caregivers,

they have been found to provide a larger number of hours of assistance to their parents than did sons (Stoller, 1983). The magnitude of this difference was most pronounced in domestic tasks and smallest in financial management and handling personal matters.

Geographic proximity also affects the role of kin family members as secondary caregivers. Provision of instrumental care including tasks such as routine daily chores or assistance with personal care requires face-to-face contact. Those daughters who resided with their elderly mothers provided eight times more help than did those who resided separately (Lang & Brody, 1983). Less proximate adult children were least likely to provide ADL (Activities of Daily Living) assistance which includes tasks such as meal preparation, housework and others (Dwyer & Coward, 1991). Suitor & Pillemar (1993) found that kin family members who lived further away were less likely to provide emotional and instrumental support than those who lived closer. Other researchers have found that children who lived within one hour of the elder were more likely to be named a helper (Stoller et al., 1992). Not only has geographic proximity been found to affect the likelihood of involvement but also the level of involvement provided by kin family members such that those daughters who shared households were more likely to provide greater amounts of assistance. This is not surprising since individuals who live in close proximity are more readily available to provide assistance and able to provide

assistance that requires face-to-face contact.

There is some competing evidence to suggest that geographic proximity does not necessarily enhance the probability that one will provide assistance. Pruncho (1990) found that local children were relatively uninvolved in the role of secondary caregiver. Among spouse caregivers who reported one local son, 69% of respondents indicated that their sons did not provide help to their ill parent. This relationship persisted regardless of the caregiver's gender. The focus of this study was on spouse caregivers of elders with Alzheimer's disease. This discrepancy may be due to an under reporting of the amount of assistance provided by adult children. Alternately, parents may be protective of their children and may not want to burden them by letting them know how much assistance is actually required. Finally, the disease may be so devastating that the adult children may deny the extent of the problem and fail to provide the appropriate level of assistance required.

Given empirical evidence, the hierarchy of obligation for secondary caregivers appears to be adult children followed by siblings and then other relatives. Preference for female relatives is evident in the research on secondary caregivers, although this gender difference is less strongly supported than in the research on primary caregivers. Depending on the type of assistance required, men may be more or less likely to be involved in the caregiving process. Kin

family members who live in close proximity are more likely to become involved in provision of care to the elderly.

A review of the caregiving literature also suggests that characteristics in addition to those proposed by Qureshi and Walker (1989) may influence involvement of kin family members in the caregiving process. For example, marital status of kin family members has been shown to affect involvement in providing assistance to the elderly. Those who were widowed, separated or divorced provided three times more assistance than married daughters (Lang & Brody, 1983). Adult children who were not married were 1.4 times more likely than those who were married to provide ADL assistance to parents (Dwyer & Coward, 1991). Stoller (1983) found that married adult daughters contributed fewer hours of assistance to their elderly parents in comparison to their non-married counterparts.

Stoller (1983) argued that competing responsibilities may impede married adult children's ability to provide assistance to their elderly parents. Lang and Brody (1983) argued that this finding may reflect the selection process that goes on within many families such that an elderly parent may rely more heavily on those children with the fewest responsibilities. Thus, married children may be exempt from assuming the caregiving role given their other responsibilities such as spouse and children.

Similarly, age of kin family members has been found to influence the

amount of assistance provided to the elderly. Older middle generation women provided significantly more hours of help to their mothers than did their younger counterparts (Lang & Brody, 1983).

Involvement in secondary caregiving is also influenced by the employment status of kin family members. Studies on the degree to which employment impinges involvement in caregiving have produced equivocal results. Some researchers have found that employed adult children were less likely to provide assistance (Dwyer & Coward, 1991; Lang & Brody, 1983). In another study, Stoller (1983) found that being employed reduced the level of assistance provided by sons but did not significantly impact the number of hours provided by daughters.

Characteristics of the primary caregiver may also affect who becomes involved in the provision of secondary care. In particular, kin family members who are involved may differ depending on whether the primary caregiver is a spouse or an adult child (Keating et al., 1994). For example, some researchers have found that spouses were more likely to be sole caregivers (Stone et al., 1987; Tennstedt et al., 1993) or to have smaller support networks (Miller & McFall, 1991) than those of adult child caregivers. Another study conducted by Matthews and Rosner (1988) revealed that adult child caregivers who provided routine assistance to their parents received some degree of assistance from their siblings.

This difference between the support provided to spouse and adult child caregivers is not surprising given that their potential source of help and expectations about obligation to care may be different. Among adult child caregivers, daughters expressed concern that their siblings were not fulfilling their obligations for providing assistance to their elderly mother (Brody et al., 1989). The most frequently cited reason for familial conflict identified by adult child caregivers was a sibling who was unwilling to provide the amount of help expected by the primary caregiver (Strawbridge & Wallhagen, 1991). In contrast, siblings of spouse caregivers would not likely be expected to provide assistance to their in-laws. The hierarchy of obligation predicts that close relatives are preferred over distant relatives. Siblings of spouse caregivers are more distant than siblings of adult child caregivers in terms of their kinship relationship to the frail elder. Children are clearly seen as the first line of assistance for elderly people (Qureshi and Walker, 1989).

The social construction of spouse and adult child caregivers' caregiving families may also be different given that their potential sources of support may be different. Given the different caregiving families and expectations about obligation to care, it not surprising that the helping networks of spouse caregivers are smaller in comparison with adult child caregivers.

Gender of the primary caregiver must also be taken into account when

examining the relationship between kinship relationship of kin family members to primary caregiver and their involvement in caregiving. Husband caregivers were more likely to receive assistance with caregiving than wife caregivers (Stone et al., 1987; Pruncho & Resch, 1989). Consequently, female spouse caregivers may be at greater risk for isolation in the caregiving process.

Age of primary caregiver has also been shown to influence the size of the caregiving family. For example, Miller and McFall (1991) found that caregivers in the youngest age category reported the largest number of informal helpers. Many of the caregivers in this category were adult children. The researchers attributed this finding to the large number of grandchildren providing assistance. Individuals in the younger age category appear to have a greater source of potential helpers in comparison to those individuals in the older age category.

Marital status of the primary caregiver has also been found to be related to the size of the caregiving family. For example, married women have been found to have more people helping with the care of their parents than did separated, divorced and never married women (Brody, Litvin, Hoffman, & Kleban, 1992). Further, married and remarried women reported that they received significantly more social support than those women without husbands. Separated, divorced and never married women may be at greater risk for providing care alone. This study provides evidence to suggest that caregiving responsibilities fall

disproportionately to formerly married or never married women.

Characteristics of frail elders have also been identified in previous research as important predictors of which kin family members become involved in provision of secondary care. For example, marital status of the frail elder appears to influence the participation of kin family members in elder care. Adult children were found to more likely to be involved in providing assistance to their parents when the frail elder was not married (Dwyer & Coward, 1991). Those frail elders who had experienced a marital disruption (e.g. widowhood, divorce or separation) or who had never married were more likely to receive help from siblings than those who were married (Cicerelli, Coward & Dwyer, 1992). Married frail elders are most likely to rely heavily on their spouses for assistance.

Gender of the ill relative has also been found to affect who becomes involved in the caregiving process. When elderly individuals identified a helper other than a spouse, they usually named someone of the same sex (Lee, Dwyer & Coward, 1993; Stoller, 1990). With other variables controlled, sons were more likely to provide assistance with tasks such as feeding, dressing and bathing to fathers than to mothers. Given that women live longer than men and the tendency toward care recipients' preference for a helper of the same sex, it is not surprising that women dominate as secondary caregivers.

III. Research Questions

A review of the caregiving literature suggests that, although extensive research has focused on care to the elderly, the caregiving literature is incomplete. Much attention has been directed towards the role of the primary caregiver in provision of care to the elderly. There is evidence to suggest that the selection of primary caregivers occurs in accordance with the hierarchy of obligation proposed by Qureshi and Walker (1989). That primary care to the elderly is provided by a spouse or adult child and female relatives are preferred to male relatives is well established. While a gender difference is evident in research on primary caregivers, men are more equally involved as spouse caregivers than adult child caregivers. Thus, kinship relationship is also an important variable which influences the likelihood of who becomes involved in the caregiving process.

Although researchers often refer to the notion of family caregiving, exactly which kin family members are involved remains unclear. There is some evidence to suggest that care of the elderly is a shared rather than sole responsibility of the primary caregiver. However, little attention has been directed towards examining which kin family members are part of the caregiving family. It has been suggested that preference for secondary caregivers also appears to operate according to the hierarchy of obligation proposed by Qureshi and Walker (1989).

Yet, a review of the literature revealed that no researchers have

systematically tested the hierarchy of obligation proposed by Qureshi and Walker (1989) to examine the likelihood of involvement of kin family members in the caregiving process. Thus, the current literature review is a compilation of research from which pieces suggest that the hierarchy of obligation fits to predict selection of secondary caregivers.

While there has been an assumption within the caregiving literature that if kin family members exist, they are involved in provision of care to the elderly, few studies have directly examined the relationship between kin families and caregiving families. It is unclear whether a large or small proportion of kin family members are involved in provision of care to the elderly. This gap in the literature requires further examination. Information obtained on the proportion of kin family members involved in provision of care to the elderly would be useful at both a practical and policy level.

Based on the conceptual framework and review of the caregiving literature, the main research question was: Does the hierarchy of obligation predict involvement of kin family members as secondary caregivers to relatives with Alzheimer's disease?

Out of this main interest, the following research questions were examined:

1. Is there a difference in the age and gender of the ill relative of spouse and adult child primary caregivers?

Hypothesis 1

There is a difference between spouse and adult child primary caregivers in their gender of the ill relatives.

Hypothesis 2

There is a difference between spouse and adult child primary caregivers in the age of their ill relatives.

2. Are there any differences in the characteristics of spouse and adult child primary caregivers?

Hypothesis 3

There is a difference in the gender of spouse and adult child primary caregivers.

Hypothesis 4

There is a difference in the age of spouse and adult child primary caregivers.

Hypothesis 5

There is a difference in the kinship relationship to ill relative of spouse and adult child primary caregivers.

Hypothesis 6

There is a difference in the employment status of spouse and adult child primary caregivers.

3. Are there any differences in the size of the kin family and caregiving family of spouse and adult child primary caregivers?

Hypothesis 7

There is a difference in the size of the kin family of spouse and adult child primary caregivers.

Hypothesis 8

There is a difference in the size of the caregiving family of spouse and adult child primary caregivers.

The primary interest of this study was on the involvement of kin family members in the caregiving process. The following two research questions addressed this interest:

4. What are the characteristics (by gender, age, kinship relationship, marital status and geographic proximity) of members of the kin family for spouse and adult child primary caregivers?

5. What percentage of the kin family members (by gender, age, kinship relationship, marital status and geographic proximity) are part of the caregiving family among spouse and adult child primary caregivers?

Hypothesis 9

Female relatives are more likely than male relatives to be involved in provision of care.

Hypothesis 10

Close kin are more likely to be involved in provision of care than more distant kin.

Hypothesis 11

Proximate kin are more likely to be involved in provision of care than kin living further away.

Hypothesis 12

Kin family members who are not married are more likely to be involved in provision of care than those who are married.

Based on a review of the caregiving literature, there are distinct differences between spouse and adult child caregivers in terms of the configuration of both their kin and caregiving families. Consequently, all analyses were done separately for these two caregivers groups.

Chapter 4

Methodology

The Caring Project

This study was completed using secondary data from a prospective, longitudinal study entitled The Caring Project. This project was funded through the NHRDP, Health Canada. The Caring Project examined the dynamics of family caregiving to relatives with Alzheimer's disease, particularly its' impact on the primary caregiver's decision to institutionalize. This project was conducted by Dr. Sharon Warren, Faculty of Rehabilitation Medicine, Dr. Norah Keating, Department of Human Ecology, Dr. Dana Wertenberger, Faculty of Nursing at the University of Alberta, and Dr. Michael Grace, Faculty of Medicine.

Participants in this project were the primary caregivers of relatives with Alzheimer's disease in Alberta. The primary caregiver was defined as the family member most responsible for the provision of care for the ill relative. Primary caregivers were residents of Alberta. Ill relatives had been diagnosed with Alzheimer's disease by a physician and were living in the community at the time of the first interview.

A convenience sample was drawn from sources including referrals from the physician or nurse at the Geriatric Outpatient at the Edmonton General Hospital, the University of Alberta Hospitals, Edmonton Board of Health Home Care

Division, Adult Day Support Programs and through ads in the newspapers.

Criteria for inclusion in this study included: 1) the ill relative must be diagnosed or confirmed with AD by a physician, 2) the AD relative must be living in the community, 3) the primary caregiver must be living in Alberta, and 4) the primary caregiver must be a relative of the AD patient.

Three interviews with the primary caregiver were conducted at one year intervals. Interviews were primarily structured and followed an interview schedule. During the first interview, participants completed a family tree and the interview schedule. Information was gathered on characteristics of kin family members including their gender, age, geographic proximity from the primary caregiver and marital status, contact with family members, help provided by family members, coping, social relationships, support related to caregiving and burden.

The Caring Project has been passed by the University of Alberta ethics review committees. As well, before recruitment of primary caregivers began from any of the facilities or organizations, a committee or Board reviewed the project proposal and it passed an ethics review of that organization or facility.

I. The Present Study

The purpose of this research study was to apply the hierarchy of obligation to understand the involvement of kin family members as secondary caregivers to relatives with Alzheimer's disease. This section outlines the sample, sampling

methodology, measures employed, procedure, ethical issues, limitations, and data analysis.

Sample

The source of data for this study was the initial interview with 104 participants: 52 spouse and 52 adult child primary caregivers.

Data were drawn from three areas in the first interview. The majority of the first interviews were conducted by Karen Kerr, Caring Project Coordinator. These interviews were conducted in the community. The three areas from which data were taken included:

1. Demographic information on ill relatives and primary caregivers

Demographic information on the characteristics of the ill relatives and primary caregivers was obtained during the first interview. This information included their gender, age, relationship of primary caregiver to ill relative, marital status and employment status. Refer to Table 1 for a summary of the demographic data on the AD relatives and primary caregivers.

2. Family Tree

Information regarding kin family members was collected through the use of a family tree obtained during the first interview. The family tree was designed by Dr. Norah Keating of the Caring Project Team. For adult child caregivers, information was gathered on siblings of the caregiver and spouse's siblings, their

maternal and paternal aunts and uncles, children and grandchildren. For spouse caregivers, information was collected on siblings of the caregiver and AD relative, children, and grandchildren. Demographic information on kin family members included kinship relationship to primary caregiver, age, marital status, gender and geographic proximity to primary caregiver. Refer to Appendix A and B for copies of the two family trees.

3 Emotional and Instrumental Help Provided by Family Members

The primary caregivers indicated whether they received assistance from kin family members (yes or no) on a series of instrumental and emotional tasks. Scott, Roberto and Hutton (1986) examined family support from the perspective of the primary caregiver. All types of instrumental assistance received from family members were recorded. Most of these tasks were included in the interview schedule employed in the Caring Project. This section was referred to as the Help Provided by Family Members. For use of this list in the Caring Project, some items were deleted or altered while others were added as per the recommendations of the Caring Project Team. In particular, Tasks 1 through 9 from Part A and Task 1 from Part B were taken from Scott et al. (1986). The remaining tasks were generated by Caring Project Team. These items were based on the research literature on family support, in particular, instrumental and emotional help.

This list assessed both the emotional and instrumental help provided by kin family members to the primary caregiver. According to Scott et al. (1986), instrumental support was defined as 'concrete' forms of help such as financial assistance, physical care and others. Primary caregivers stated whether they received assistance from their kin family members (yes or no) on a series of emotional and instrumental tasks.

For the purposes of the present study, the number of 'yes' responses were summed in order to obtain scores on both emotional and instrumental help received. A kin family member was considered to be a helper if he or she provided assistance with one or more emotional or instrumental tasks. The rationale for defining helpers in this way was based on the fact that involvement was a dichtomous variable and coded as yes or no. There was no way of determining if one task was more or less than the others. This protocol does not indicate the level of support provided to the primary caregiver. Information on the amount of assistance provided by kin family members was not obtained. This protocol has not been standardized; no reliability or validity data exist on this measure. However, this protocol has face and content validity as determined by the experts involved in the Caring Project.

II. Data Sets

The original data set consisted of 109 primary caregivers. Because most

of the research questions could not be answered using the original data set, the data were reorganized. For the purpose of this study, data from 104 spouse and adult child primary caregivers from the first interview and from the revised data set were used. The revised data set, referred to as the Family Data set, consisted of each kin family member representing a case. The revised Family Data set was comprised of 561 kin family members. Kin family members included in this data set were: wife, husband, sons, daughters, sisters, and brothers of the primary caregiver.

The Family Data set consists of information for each kin family member on the following: age, gender, marital status, kinship relationship to primary caregiver, geographic proximity to primary caregiver, and involvement in providing assistance on a series of emotional and instrumental tasks.

III. Operational Definitions and Data Analyses

Research Question 1: Is there a difference in the age and gender of the ill relative of spouse and adult child primary caregivers?

The first research question in this study was concerned with the characteristics of the ill relatives. Characteristics of interest included their gender and age. This information was gathered during the first interview.

Descriptive statistics and frequencies were calculated on these two characteristics. The test of significance used in this part of the analyses to

compare the percentage of ill relatives by gender was chi-square. The chi-square is essentially a measure of how different the observed frequencies are from the expected frequencies (Pagano, 1990). The main purpose of chi-square is to determine whether two categorical variables are independent or related. The cut off for significance was $p > .05$. In order to compare the mean age of the ill relatives, a t test was completed. The main purpose of a t test was to determine whether there was a significant difference in the mean age of the ill relatives of spouse and adult child primary caregivers.

Research Question 2: Are there any differences in the characteristics of spouse and adult child primary caregivers?

The second research question focused on characteristics of spouse and adult child primary caregivers. Characteristics of interest included their gender, age, relationship of primary caregiver to ill relative and employment status. This information was also obtained during the first interview.

Descriptive statistics and frequencies were also calculated in order to answer this research question. The test of significance used to compare the percentage of primary caregivers by gender, kinship relationship and employment status was chi-square. The cut off for significance was $p > .05$. A t test was employed to assess whether there was a significant difference in the age of primary caregivers.

Research Question 3: Are there any differences in the size of the kin family and caregiving family of spouse and adult child primary caregivers?

The third research question was concerned with whether there were differences in the size of the kin family and caregiving family for spouse and adult child primary caregivers. Descriptive statistics and frequencies were calculated by counting the number of kin in the family tree and the number of kin family members identified as providing instrumental or emotional help for spouse and adult child primary caregivers. The test of significance employed in this part of the analyses was chi-square. The cut off for significance was $p > .05$.

First, the measure of the size of the kin family was ascertained by counting all existing family members in five kin categories: spouses, sons, daughters, brothers and sisters. Other kin family members such as mother, father, mother-in-law, father-in-law, paternal and maternal aunts and uncles, spouse's siblings, and grandchildren were excluded from this study. The decision to exclude these kin family members was both practical and based on a review of the caregiving literature.

First, the practical reason was based on the data collection. Adult child primary caregivers were asked to identify their maternal and paternal aunts and uncles, their children and grandchildren as well as their siblings and spouses' siblings. Spouse primary caregivers, on the other hand, were asked to identify

their siblings and spouses' siblings in addition to their children and grandchildren. Thus, comparable data on the kin family members for spouse and adult child primary caregivers were not available with the exception of siblings and children. Second, a review of the caregiving literature demonstrated that these other kin family members have been shown to play a less prominent role in caregiving (Stone et al., 1987; Qureshi and Walker, 1989).

The size of the caregiving family was also calculated in this study. Membership in the caregiving family was determined by the list entitled "Help Provided by Family Members." Refer to section entitled "Emotional and Instrumental Help Provided by Family Members" for a summary of how involvement in caregiving was ascertained in the present research. The size of the caregiving families was determined by counting the number of kin family members in five kin categories (spouse, sons, daughters, brothers and sisters) named as providing at least one type of either instrumental or emotional support. This method of determining family involvement provided researchers with a picture of which members of families are to be at least minimally involved in the caregiving process. It did not provide information on the level of care provided by kin family members.

The percentage of kin family members helping and not helping was then calculated. The percentage of kin family members helping was determined by

dividing the number of helping kin family members by the total kin family members for spouse and adult child primary caregivers. The mean number of kin family and helping kin family members was calculated for spouse and adult child primary caregivers. The mean number of kin family members was calculated by dividing the total number of kin family members by the total number of primary caregivers for spouse and adult child primary caregivers. The mean number of helping kin family members for spouse and adult child primary caregivers was determined by dividing the number of helping kin by the number of primary caregivers.

Research Question 4: What are the characteristics (by gender, age, kinship relationship, marital status and geographic proximity) of members of the kin family for spouse and adult child primary caregivers?

The size of the kin and caregiving family begins to provide an understanding of the configuration of kin families and caregiving families for spouse and adult child caregivers. However, the size of the kin family and caregiving family for spouse and adult child caregivers was based on absolute numbers. In order to obtain a more accurate picture of who comprised the caregiving family, attention must be directed to available and helping kin family members. Accordingly, the fourth research question focused on the percentages of kin family members on a series of characteristics.

The test of significance used for this question to compare the percentage

of kin family members by gender, kinship relationship, marital status and geographic proximity for spouse and adult child primary caregivers was chi-square. A t test was used to determine if there was a significant age difference in the kin family members of spouse and adult child primary caregivers.

Research Question 5: What percentage of the kin family members (by gender, age, kinship relationship, marital status and geographic proximity) are part of the caregiving family among spouse and adult child primary caregivers?

The final research question focussed on the percentage of kin family members involved in providing instrumental or emotional help for spouse and adult child primary caregivers. The percentage of kin family members involved in caregiving were calculated by dividing the number of helping kin by the number of existing kin family members. Percentages of kin family members helping were calculated by gender, kinship relationship to primary caregiver, marital status and geographic proximity to primary caregiver using the Family Data set. The mean age of helping kin of spouse and adult child caregivers was also calculated.

The test of significance used in this part of the analyses to compare the percentage of kin family members involved in provision of care by gender, kinship relationship, marital status and geographic proximity for spouse and adult child primary caregivers was chi-square. A t test was completed to assess if there was an age difference in the helping kin of spouse and adult child primary caregivers.

Chapter 5

Results

Although the primary focus of this study was on the involvement of kin family members in provision of care to relatives with Alzheimer's disease, it is important to begin the analyses by examining major characteristics of the ill relatives as well as their primary caregiver. Researchers have found that characteristics of the ill relative and primary caregiver such as gender influence who becomes involved in the caregiving process. Thus, an understanding of the characteristics of the ill relative and primary caregiver is essential to understanding the involvement of kin family members as secondary caregivers. It is also imperative to examine the spouse and adult child primary caregivers separately since they are likely to have structurally different kin families and caregiving families. For example, spouse primary caregivers are of a different age cohort than adult child primary caregivers and are more likely to have two generations of kin family members who are potential helpers. Thus, all analyses were performed separately for spouse and adult child primary caregivers.

I. Is there a difference in the age and gender of the ill relative of spouse and adult child primary caregivers?

The first research question was focussed on determining if there was a difference in the gender and age of the ill relative for spouse and adult child

primary caregivers. A summary of the characteristics of ill relatives is presented in Table 1. As hypothesized, a difference in the gender of the ill relative was found between spouse and adult child primary caregivers. A greater percentage of ill relatives among adult child primary caregivers were female. Among adult child primary caregivers, 82.7% of the ill relatives were female in comparison with only 30.8% for spouse primary caregivers. As expected, an age difference was also found between the ill relatives of spouse and adult child primary caregivers. The mean age of the ill relatives of spouse and adult child primary caregivers was 73.7 and 78.1 respectively. Ill relatives of adult child primary caregivers were older than those of spouse primary caregivers. The findings support the hypotheses that there are distinct differences in the gender and age of ill relatives of spouse and adult child primary caregivers.

II. Are there any differences in the characteristics of spouse and adult child primary caregivers?

The second research question focused on the differences in the characteristics of spouse and adult child primary caregivers. These data are also summarized in Table 1.

It was hypothesized that a difference in the gender of spouse and adult child primary caregivers would be found. A review of the results revealed that women are predominant as primary caregivers. The findings from Table 1 support

results from previous researchers which suggests that the responsibilities of primary care to the elderly fall disproportionately on women. As illustrated in Table 1, women are more likely than men to assume the role of primary caregiver. Among spouse primary caregivers, women comprised 69.2% of the primary caregivers. For adult child primary caregivers, 94.2% of the primary caregivers were female. These results support the notion that caregiving is deemed to be women's work. The magnitude of this gender difference was most pronounced for adult child primary caregivers. It is interesting to note that men comprised 30.8% of spouse primary caregivers.

The research findings support the hypothesis that there is an age difference between these two caregiver groups. As indicated in Table 1, the mean age for spouse primary caregivers was 69.9 and for adult child primary caregivers was 46.0. This difference was not surprising and supports that spouse and adult child primary caregivers are from different generations.

The kinship relationship of the primary caregiver to the ill relative is also presented in Table 1. The results support the hypothesis that there is a difference in the kinship relationship of the primary caregiver to the ill relative. Among spouse primary caregivers, 69.2% of primary caregivers were wives. Daughters comprised 80.8% of the adult child primary caregivers.

In line with our expectations, a difference was found in the employment

status of spouse and adult child primary caregivers. Adult child primary caregivers were more likely to be employed. As indicated in Table 1, 5.8% of spouse primary caregivers and 73.1% of adult child primary caregivers were employed.

III. Are there any differences in the size of the kin family and caregiving family of spouse and adult child primary caregivers?

The third research question was focused on the differences in the size of the kin family and caregiving family of spouse and adult child primary caregivers. Contrary to expectation, a significant difference in the size of the kin family of spouse and adult child primary caregivers was not found. The mean number of kin family members for spouse and adult child primary caregivers was 5.5 and 5.3 respectively. Similarly, support for a significant difference in the mean number of helping kin for spouse and adult child primary caregivers was not found. The mean number of helping kin for spouse and adult child primary caregivers was 3.6 and 3.4 respectively.

A secondary interest in the present study was the relationship between the kin family and caregiving family of spouse and adult child primary caregivers. Based on the above mentioned findings, the assumption that the kin family and caregiving family are synonymous is challenged. Further support to challenge this assumption is presented in Table 2. Among spouse primary caregivers, 64.8% of the kin family members and 63.9% of the kin family members of adult child primary

caregivers provided assistance.

IV. What are the characteristics (by gender, age, kinship relationship, marital status and geographic proximity) of members of the kin family for spouse and adult child primary caregivers?

The previous section provides a beginning understanding of the differences between the size of the kin family and caregiving family of spouse and adult child primary caregivers. However, in order to obtain a clear and more accurate picture of who is involved in provision of secondary care, it is necessary not only to consider who is involved but also who is available to provide assistance. Thus, we will proceed by comparing the kin family of spouse and adult child primary caregivers.

First, this section focused on a description of the composition of the kin family for spouse and adult child primary caregivers. Table 3 provides an overview of the percentage of kin family members by gender, age, kinship relationship, marital status, and geographic proximity for spouse and adult child primary caregivers.

Table 3 shows that the majority of kin family members for spouse primary caregivers were female. Among spouse primary caregivers, 57.5% of the kin family members were female. For adult child primary caregivers, 39.1% of the kin family members were female. Kin family members of spouse primary caregivers

were more likely to be older than those of adult child primary caregivers. The mean age of kin family members for spouse and adult child primary caregivers was 51.7 and 35.3 respectively.

Table 3 also contains comparisons of kin family members by kinship relationship. Some significant differences can be observed in the composition of kin families of spouse and adult child primary caregivers. However, it should be noted that comparison of these two caregivers must be done with caution given that spouse primary caregivers had four kinship categories while adult child primary caregivers had five.

Differences in the marital status of kin family members of spouse and adult child primary caregivers were also apparent. Spouse primary caregivers were more likely to have married kin family members than were adult child primary caregivers. For spouse primary caregivers, 72.1% of kin family members of spouse primary caregivers were married in comparison with 49.6% of kin family members of adult child primary caregivers.

Kin family members of adult child primary caregivers were more likely to live at home. Table 3 provides a comparison of the distribution of kin family members by geographic proximity for spouse and adult child primary caregivers. Adult child primary caregivers reported 27.5% of their kin resided in the same household in comparison with 2.4% of spouse primary caregiver.

V. What percentage of the kin family members (by gender, age, kinship relationship, marital status and geographic proximity) are part of the caregiving family among spouse and adult child primary caregivers?

The previous section focussed on a description of potential helpers. The final research question was concerned with the percentage of kin family members by gender, age, kinship relationship, marital status and geographic proximity that were involved in provision of secondary care for spouse and adult child primary caregivers. Thus, a comparison of the involvement of kin family members taking into consideration both those involved in caregiving as well as those potentially available to help was completed. These comparisons are shown in Table 4.

Partial support for the hypothesis that female relatives are more likely to be involved in provision of care was found. As illustrated in Table 4, for spouse primary caregivers, the majority (60.2%) of helpers were female. In contrast, the majority (61.3%) of helpers of adult child primary caregivers were male. An age difference was found between helping kin family members of spouse and adult child primary caregivers. The mean age of helping kin family members for spouse and adult child primary caregivers was 46.0 and 34.8 respectively.

When the composition of the caregiving family by kinship relationship was reviewed, some differences were found. It was hypothesized that close kin would be more likely to be helping than more distant kin. However, evidence to support

this hypothesis was only found among spouse primary caregivers. Among spouse primary caregivers daughters comprised 41.8% of the helpers. In comparison, 20.6% of the helpers of adult child primary caregivers were daughters.

Siblings of spouse primary caregivers were a small proportion of helpers. In particular, brothers only comprised 5.1% of the helpers of spouse primary caregivers. In contrast, siblings of adult child primary caregivers comprised a larger proportion of helpers than the other kin categories. Additionally, contrary to expectation, for adult child primary caregivers, spouses (19.1%) comprised the third largest category of helping kin.

Unexpectedly, the majority (73.5%) of helping kin of spouse primary caregivers were married in comparison with those of adult child primary caregivers.

The final characteristic of kin family members that was examined in relation to involvement in caregiving was the geographic proximity of kin family members to the primary caregiver. As expected, those kin who lived closer to the primary caregiver were more likely to be involved in provision of care to a relative with AD. However, adult child primary caregivers had a higher proportion of their helping kin residing in the same household whereas for spouse primary caregivers, the largest proportion of their helping kin lived within 50 miles. More specifically, 23.7% of the helping kin of adult child primary caregivers versus about 3.6% of those of spouse primary caregivers resided in the same household.

Chapter 6

Discussion

The previous chapter presented a descriptive profile of the kin family and caregiving family for spouse and adult child primary caregivers of relatives with AD. Characteristics of the ill relatives and primary caregivers were compared followed by a review of the size of the kin family and caregiving family for spouse and adult child primary caregivers. Finally, characteristics of the kin family members and percentages of those kin family members involved in helping were examined.

In the present chapter, the research findings are discussed according to the five research questions. Each question will be dealt with separately. Possible explanations to account for the research findings are offered. Limitations inherent in the present research and suggestions for future research conclude the discussion.

Overview

The main purpose of the present study was to examine who are members of the caregiving family. Our understanding of the nature of family caregiving has been limited. First, most investigators have focused on the role of the primary caregiver in provision of care to the elderly. Second, those researchers which have examined the role of the secondary caregivers have narrowed their focus to

a single type of family member (e.g. adult children, or sons versus daughters) (Coward, Horne, & Dwyer, 1992). Moreover, researchers have focused on family caregiving one variable at a time (e.g. impact of kinship relationship on patterns of caregiving) (Tennstedt et al., 1993). Although these studies provided a beginning understanding of the role of secondary caregivers, they did little to advance our knowledge of family caregiving and specifically, its composition. In particular, Coward et al. (1992) argued that there is a great deal that we do not know about gender (both of caregiver and ill relative) as well as the demography of family care to the frail elderly.

The findings from this study are useful in bridging these knowledge gaps in the caregiving literature. Keating et al. (1994) argued that information pertaining to the size and composition of the kin family and caregiving family could provide insight into the nature and extent of involvement of kin family members. This knowledge is essential in order to develop more informed policy related to the needs of the elders and their families.

This study focused on how structural characteristics of kin family members influence their involvement in the caregiving process. The social construction of the caregiving family is dependent on a variety of factors beyond characteristics of the elder, primary caregiver and kin family members. For example, how caregiving is defined will inevitably lead to the inclusion or exclusion of various kin

family members as caregivers (Keating et al., 1994). Additionally, family history is also another factor which impacts on who becomes involved in the provision of care. As a consequence, findings from the present study assist in understanding the impact of characteristics of kin family members on the social construction of caregiving families.

I. Is there a difference in the age and gender of the ill relative of spouse and adult child primary caregivers?

Findings from the caregiving literature suggest that characteristics of the ill relative affect who becomes involved in caregiving. In order to obtain a picture of the nature of family caregiving and the composition of the caregiving family, it is important to begin by examining the characteristics of the ill relative of spouse and adult child primary caregivers. The first research question focused on the degree to which characteristics of ill relatives differed for spouse and adult child primary caregivers.

In summary, these data supported the hypothesis that there are distinct differences in the characteristics of ill relatives of spouse and adult child primary caregivers. Specifically, adult child primary caregivers reported a higher percentage of female ill relatives. This may be related to the finding that most older women do not have spouses and therefore, their children assumed responsibility for primary care. Based on the hypothesis that kin family members

of the same gender as the ill relative are more likely to become involved in provision and the predominance of female ill relatives, one would expect a greater percentage of female kin family members involved in helping among adult child primary caregivers. Additionally, ill relatives of adult child primary caregivers were more likely to be older than those of spouse primary caregivers. This age difference may be related to the finding that ill relatives of adult child primary caregivers are more likely to be widowed and therefore, further along in the aging process.

These findings are in line with those found by previous investigators (Stone et al., 1987). Based on previous findings of other researchers suggesting that characteristics of the ill relative affect involvement of kin family members in caregiving and the differences found in the present study between these two caregiver groups, the composition of their caregiving families is likely to differ. For example, among adult child primary caregivers, spouses of the ill relatives are not likely available to become involved in helping.

II. Are there any differences in the characteristics of spouse and adult child primary caregivers?

The second question was concerned with comparing the characteristics of spouse and adult child primary caregivers. This information is important as the choice of primary caregiver influences the selection of other kin family members.

Shifting the focus to the primary caregivers, the results from this research reinforced the prevailing assumption that primary care of the elderly falls disproportionately to women. Women tend to marry older men. It has been argued that the higher mortality rates of men and age stratification, in part, account for higher incidence of women as primary caregivers. While this explanation may account for the gender difference for spouse caregivers, further explanation must account for the gender difference for adult child primary caregivers. Most of the theories proposed to date tend to suggest that women are more nurturing and this characteristic lends themselves naturally to role of caregiver. Other sociological theories focus on gender role expectations which suggest that caregiving is in line with their role as women. Walker (1992) has argued that these theories are problematic in that they legitimate existing structures or patterns of caregiving. A post modern feminist perspective would challenge these explanations for this gender difference and suggest that it must be understood within a societal and political context.

Although the research findings suggest a predominance of women as primary caregivers, there is some evidence to suggest that men become involved as primary caregivers. The gender difference is less pronounced among spouse primary caregivers. Older women are more likely to assume the role of primary caregiver than older men. This result reflects, in part, that most older men who

are ill have spouses while older women who are ill do not. Therefore, because most older women do not have spouses, it is not surprisingly that men play a less prominent role of men as spouse primary caregivers. The effect of gender on provision of primary care appears to differ depending on whether the primary caregiver is a spouse or an adult child. Similar to other studies, an age difference was found between spouse and adult child caregivers.

The results regarding the kinship relationship of the primary caregiver to the ill relative are consistent with those of other investigators (Stone et al., 1987). Half of the primary caregivers were spouses and the other half were adult children. Spouses and daughters played a prominent role in provision of primary care. As suggested, these data support previous research findings suggesting that men are more involved as spouse primary caregivers in comparison with adult child primary caregivers. Among adult child primary caregivers, sons comprised the smallest kin category of primary caregivers.

The greater involvement of men as spouse primary caregivers may be related to familial obligation. Clearly, there is evidence in the caregiving literature and an assumption amongst theorists that spouses are the first line of support to the frail elderly. Spouses are seen as obligated to provide care. Male spouse primary caregivers are older and likely retired and are not only obligated but also available to provide care to their ill spouses. Sons, on the other hand, are younger

and likely employed and may be less obligated and able to provide primary care. Sons may be seen as being 'off the hook' in terms of responsibilities to provide care. Alternately, sons may be less available to provide care due to other competing responsibilities (e.g. employment, social and child care.

Little is known about how the gender of the ill relative interacts with the gender of caregiver to influence patterns of caregiving. There is some evidence to suggest that elders tend to be more likely to name kin family members of the same gender (Barusch & Spaid, 1989: Stoller, 1990). The majority of ill relatives of adult child primary caregivers were female. Therefore, evidence for the same-sex hypothesis provides an alternative explanation to account for the predominance of daughters primary caregivers.

Given the age difference between these two groups, the finding that adult child primary caregivers were more likely to be employed was not surprising. Since the mean age of spouse primary caregivers was 69.9, many of the spouse caregivers were likely retired and may account for this difference. Additionally, there are generational differences between these two caregivers groups and many of the women from the older generation probably had not been employed.

III. Are there any differences in the size of the kin family and caregiving family of spouse and adult child primary caregivers?

The third research question was concerned with the size of the kin family

and caregiving family. An assumption implicit in the caregiving literature as well as in policies is that if families exist, they are involved in provision of care to the elderly. Yet, little research has specifically focused on the size of the kin family and caregiving family. One of the interests in the present study was to test this assumption and determine the number of kin family members involved in providing secondary care to relatives with AD. As well, another area of interest was the difference in the size of the caregiving family of spouse and adult child primary caregivers.

The present results suggest that the majority of kin family members are involved in provision of secondary care. Both spouse and adult child primary caregivers reported that approximately 64% of their kin family members were involved in provision of care. In line with the findings of previous researchers, the results of the present study revealed that care of the elderly is a shared rather than the sole responsibility of the primary caregiver (Matthews & Rosner, 1988); Stephens & Christianson, 1987). Most of the primary caregivers reported that they received at least some assistance with caregiving. For example, spouse and adult child primary caregivers received at least some help caring for their relatives with AD, with a mean of 3.6 and 3.4 helpers respectively.

Although the present findings provide evidence suggesting that kin family members are involved in provision of secondary care, not all kin family members

are involved in this process. The present results challenge the assumption that the kin family and caregiving family are similar. Findings from this research question are important especially if policy makers have formulated policies based on a false assumption. Policy makers and practitioners could utilize the findings from the present research to make more informed decisions and policies which in turn, could better meet the needs of the elderly and their families. For example, in recognizing that not all kin family members are involved in provision practitioners could take steps to ensure that any gaps in help received are addressed.

A review of the caregiving literature suggested that spouse primary caregivers may be at greater risk for providing care alone. Contrary to expectation, a review of the present research findings suggests that spouse and adult child primary caregivers had an equal proportion of kin family members involved in helping. Approximately 64% of kin family members of spouse and adult child primary caregivers are involved in provision of secondary care.

Overall, this study reveals that some kin family members were involved in provision of care. However, it is important to note that this study was unable to assess the level of involvement provided by kin family members. Future research should take into consideration the level of involvement in order to obtain a more comprehensive understanding of the nature of family caregiving.

IV. What are the characteristics (by gender, age, kinship relationship, marital status and geographic proximity) of members of the kin family for spouse and adult child primary caregivers?

The fourth research question was focused on the characteristics of the kin family for spouse and adult child primary caregivers. With respect to the gender, the majority of kin family members of spouse primary caregivers were female. Adult child primary caregivers reported a lower percentage of their kin family members being female. This finding may be related to the fact that most of the primary caregivers were female and therefore, would be excluded from the analyses on secondary care.

The findings further suggest that siblings, in particular, brothers comprised a small proportion of the kin family for spouse primary caregivers. This finding may be related to the age of these kin family members. Kin family members of spouse primary caregivers were older than those of adult child primary caregivers. Consequently, some of the brothers of spouse primary caregivers may already be deceased and therefore, unavailable to provide care. Additionally, brothers of spouse primary caregivers may be unable to provide help due to their own deteriorated health status.

Evidence was also found to suggest a difference between spouse and adult child primary caregivers in terms of the marital status of their kin family members.

That a smaller percentage of adult child primary caregivers were married is not unusual based on the finding that they were significantly younger than kin family members of spouse primary caregivers. Many of the kin family members of former are likely dependent and live at home. There was evidence to support this explanation as kin family members of adult child primary caregivers were more likely to reside in the same household than those of spouse primary caregivers.

V. What percentage of the kin family members (by gender, age, kinship relationship and proximity) are part of the caregiving family among spouse and adult child primary caregivers?

The main objective of this study was to identify what characteristics of kin family members affect their involvement in provision of care to relatives with AD. Findings from those of previous researchers suggest that characteristics of kin family members influence who becomes involved in provision of secondary care. However, researchers have not yet systematically examined the impact of these characteristics on involvement in caregiving. Findings from the present research advance our knowledge of the composition of the caregiving family by providing a description of the relationship between a series of variables and involvement in provision of secondary care to relatives with AD.

Analysis of the present data revealed distinct differences between spouse and adult child primary caregivers. The first hypothesis predicted that female

relatives would be more likely to be involved in provision of care. Partial support for this hypothesis was found. Spouse primary caregivers reported a higher proportion of female caregivers than did adult child primary caregivers. Men, however, demonstrated greater involvement in caregiving among adult child primary caregivers. This result fits with findings from previous investigators suggesting that men are more likely to provide sporadic help (Stone et al., 1987). This finding may be related to the higher proportion of male kin available to provide help among adult child primary caregivers. Together, spouses, brothers and sons comprised approximately 60% of the kin among adult child primary caregivers. In comparison, sons and brothers comprised about 42.5% of the kin family among spouse primary caregivers.

Another explanation to account for this finding may be related to familial obligation to provide care to the elderly. This will be discussed next when the composition of the caregiving family by kinship relationship is reviewed. Clearly, the effect of gender of kin family members appears to differ depending on whether the primary caregiver was a spouse or an adult child.

The tenth hypothesis predicted that close kin would be more likely to be involved as caregivers. A difference in the distribution of helping kin by kinship relationship was found between spouse and adult child primary caregivers. A high proportion (41.8%) of helping daughters was reported among spouse primary

caregivers. The hierarchy of obligation predicts that the spouse is the first line of assistance to the frail elderly. However, among spouse primary caregivers, the spouse is the ill relative and therefore, unavailable to provide help. According to the hierarchy of obligation, daughters are the next most likely source of assistance when the spouse is unavailable. Evidence to support the hierarchy was found among spouse primary caregivers.

Contrary to expectation, the proportion of kin family members involved in caregiving among adult child primary caregivers was relatively equal. The hierarchy of obligation predicts that spouses are the first line of assistance followed by daughters. For adult child primary caregivers, the present findings do not provide support to the hierarchy of obligation. Men, both brothers and sons, are involved in helping. Their involvement in caregiving is higher than what would be expected based on the hierarchy of obligation. One needs to examine further how kinship relationship of kin family members influences who becomes involved in caregiving.

Although there is evidence to suggest that men and women are more equally involved in caregiving among adult child primary caregivers, this relationship may be mitigated by a third variable, type of help required. For example, in a study conducted by Stoller (1990), evidence was found to suggest that, among elders requiring routine assistance, men were less likely than women

to help with cooking, light chores, and laundry. To gain a better understanding of the present findings, further analyses which takes into account the type of assistance is required.

In order to account for these findings, it is necessary not only to consider the relationship of the kin family members of spouse and adult child primary caregivers to the ill relative but also the obligation of these individuals to provide care. The hierarchy of obligation predicts that close kin are more likely to become involved in caregiving than more distant kin. Upon review of the findings in Table 4, it would appear that among adult child primary caregivers, siblings (43.3%) comprised a larger proportion of helping kin than did siblings (23.5%) of spouse primary caregivers. The proportion of siblings involved in caregiving for adult child primary caregivers was calculated by omitting the category of spouses. The most pronounced difference between these two caregiver groups was the proportion of brothers involved in caregiving.

One reason that a smaller proportion of brothers of spouse primary caregivers are involved may be related to their age. As illustrated in Table 3, brothers comprise the smallest category of kin among spouse primary caregivers. Not only are there fewer brother available but this group of kin are elderly themselves and therefore, may be unable to provide care.

In terms of closeness of kin, siblings of spouse and adult child primary

caregivers appear to be in similar kinship positions. However, when one considers their relationship to the ill relative, a distinct difference between these two groups is revealed. For example, siblings of adult child primary caregivers are more closely related to the ill relative than siblings of spouse primary caregivers as the former are the iil relatives' children. In comparison, siblings of spouse caregivers are either a sister-in-law or brother-in-law of the ill relative. Consequently, the greater proportion of siblings involved in caregiving among adult child primary caregivers may be related to their greater obligation to provide care. The caregiving literature supports the notion that, following the spouse, children are the next source of assistance for elderly people (Qureshi and Walker, 1989). Further, it lends support to the hierarchy of obligation which suggests close relatives are more likely to become involved in caregiving than more distant ones. It would appear that kinship relationship of the kin family member to the ill relative is critical to understanding who becomes involved in caregiving.

With respect to the next characteristic of interest, marital status, it was predicted that kin family members who were not married would be more likely to be involved in caregiving. Contrary to expectation, among spouse caregivers, helping kin were more likely to be married.

One explanation to account for this finding may be related to the age of the kin family members of spouse primary caregivers. The findings demonstrated that

helping kin family members of spouse primary caregivers were older than those of adult child primary caregivers. It may be that, although kin family members of spouse primary caregivers are married, they are not faced with the same responsibilities such as employment and care of young children as their younger counterparts and therefore, are available to become involved in secondary care.

Another possibility lies in the structure of kin family members of adult child primary caregivers. The results demonstrated that kin family members of adult child primary caregivers are significantly younger than those of spouse primary caregivers. Kin family members of adult child primary caregivers are younger and therefore, not yet married. Consequently, there are fewer available married kin family members to become involved in provision of care.

Provision of instrumental help including tasks such as routine daily chores or assistance with personal care requires face-to-face contact. With respect to the final characteristic of interest, geographic proximity, the current findings are similar to those of other researchers suggesting that kin family members living in close proximity are more likely to be involved in provision of care.

Although there is evidence to suggest that kin family members who live in close proximity are more likely to be involved in caregiving, the relationship between geographic proximity and involvement in caregiving was different for spouse and adult child primary caregivers. For adult child primary caregivers, a

greater proportion (23.7%) of their helping kin resided in the same household whereas only a small proportion (3.6%) of helping kin of spouse primary caregivers did.

VI. Proposed Hierarchy of Obligation for Secondary Caregivers of Spouse and Adult Child Primary Caregivers

The present study was based on the underlying assumption that the caregiving family is socially constructed. This construction is impacted by a variety of factors including family history, affection, socialization, societal context, characteristics of the ill relative, primary caregiver and kin family members, obligation and others. In particular, the present study examined the impact of a series of characteristics of kin family members on their involvement in provision of secondary care. The hierarchy of obligation provided the framework from which the social construction of the caregiving family was examined.

Based on a review of the research findings, it became apparent that there were some discrepancies between who was expected to become involved in caregiving from who was reported to be involved in provision of care. The present results were not consistently in agreement with the hierarchy of obligation. Further, the necessity to examine a series of characteristics simultaneously including age and gender of ill relative and primary caregiver to assess the involvement of kin family members also became apparent.

This study was interested in determining whether the hierarchy of obligation is useful in understanding the involvement of kin family members in provision of secondary care. Despite some of the inconsistencies of the present results with the hierarchy of obligation, the hierarchy of obligation provides us with a beginning understanding of involvement of kin family members in provision of secondary care. A major finding of this study is there are distinct differences between spouse and adult child primary caregivers in terms of the characteristics of their kin families and subsequently, caregiving families.

The findings from the present research demonstrated that the hierarchy of obligation proposed by Qureshi and Walker (1989) did not apply in the same way for spouse and adult child primary caregivers. Part of this may be related to the structural differences in their kin and caregiving families such as the age difference between their kin family members. For example, the higher mean age of kin family members among spouse primary caregivers precludes some of them such as brothers who may also be frail from becoming involved in caregiving.

The kinship relationship of the kin family members to the ill relative needs to be considered. In terms of closeness of kin, siblings of spouse and adult child primary caregivers are not in the same position. Rather, the latter are more closely related to the ill relative. One of the hypotheses based on the hierarchy of obligation predicts that close kin are more likely to become involved in

caregiving than more distant ones. However, this difference makes it difficult to compare these two groups to determine whether this hypothesis is supported.

Based on the differences between these two caregiver groups, two hierarchies are proposed to account for the involvement of kin family members in provision of secondary care to relatives with AD. The following provides an overview of the hypotheses for the proposed hierarchy of obligation for spouse primary caregivers:

a) female relatives are more likely than male relatives to become involved in provision of care

b) daughters are the first line of assistance to frail elderly followed by sons

c) kin family members who are married are more likely to become involved in provision of care than those who are not married

d) proximate kin, kin living within 50 miles, are more likely to become involved in provision of care than those who are more distant

The above differs from the hierarchy of obligation proposed by Qureshi and Walker (1989) in that the spouse is not the first line of assistance to the elderly. It is similar in that female relatives and close kin are most likely to become involved in provision of care. It challenges the assumption of previous findings that kin family members who are married are more likely to become involved in provision of care.

The following is the second hierarchy of obligation proposed and associated hypotheses for adult child primary caregivers:

a) male relatives are more likely than female relatives to become involved in provision of care

b) children are the first line of assistance to adult child primary caregivers followed by spouses and then siblings

c) proximate kin, residing in the same household, are more likely to become involved in provision of care than those who are more geographically distant

This hierarchy differs from Qureshi and Walker's in that male relatives are more likely than female relatives to become involved in provision of care, and children are the first line of assistance. Contrary to the caregiving literature, according to the proposed hierarchy of obligation for adult child primary caregivers, marital status of kin family members does not affect involvement in provision of care.

VII. Limitations of the Present Study

The present research adds to the small body of caregiving literature that has focused on the configuration of caregiving families and more specifically, characteristics of kin family members who are likely to become involved in the caregiving process. Rather than examining one particular kin group, the

involvement of several kin family members was studied. These findings provide new insights as to which characteristics are important in understanding the involvement of kin family members in the provision of secondary care.

Despite the advantages and insights derived as a result of the present study, there are some problems inherent in this study. Given that this study was based on secondary data, it was limited by pre-existing data. The data used to address the current research questions were taken from one kin family member, the primary caregiver. Thus, it offers one perspective of the kin family and caregiving family. One of the underlying assumptions of the present research is that the caregiving family is socially constructed. As argued at the outset, the construction of caregiving families is not necessarily seen in the same way by all family members. For the purposes of this study, we focused on the social construction of the caregiving family from the perspective of the primary caregiver. Although the data were from an individual perspective, it provides us with information regarding the nature of family caregiving and composition of the caregiving family. In this way, it advances our current knowledge of family caregiving. Nonetheless, one must be careful not to attribute the results from this study to all members of the family.

Second, although these data provided information regarding who was involved in caregiving, the level of involvement is unavailable. Moreover, the

definition of involvement was broad as a kin family member was only required to provide help with one of several instrumental or emotional tasks. It is important to recognize that, although the data suggested that the majority of kin family members were involved in caregiving, how much each kin family member was involved remains unclear. Further, if a stricter definition of involvement in provision of secondary care had been employed, some of the kin family members identified as helpers may have been omitted. Thus, the configuration of the caregiving family is, in part, a function of the definition of involvement in provision of secondary care. Future research must not only direct attention to the level of involvement but also type of assistance provided.

Third, the present sample does not represent a simple random sample of elders residing in the community. Rather, it is a more select sample which focused on elders with AD. As a consequence, it does not provide insight to the helping networks of elders, in general. One cannot assume that caregiving families are the same across all caregiving situations. The generalizability of the current findings is therefore limited. Given the nature of the disease, one would not only expect differences in the composition of caregiving families of elders with Alzheimer's disease but also in the type and amount of assistance provided. There is evidence to suggest that the size of the helping network varies according to the level of impairment of the elder (Birkel & Jones, 1989; Stoller, 1990a;

Tennstedt et al., 1993). The purpose of this study was to determine what characteristics of the kin family affect involvement in provision of care to relatives with AD. Future research needs to explore the configuration of caregiving families and level of involvement of kin family members across different caregiving situations.

Finally, one of the variables of interest in this study which has been shown to influence which kin family members become involved in process of caregiving is their kinship relationship to the primary caregiver. According to Qureshi and Walker (1989), close relatives are preferred to more distant ones. One of the limitations implicit in the present research is that only close kin were examined. Kin categories included in this study were daughters, sons, brothers, sisters and spouses. Therefore, one cannot comment on the effect of closeness of kinship relationship of kin family members on their involvement in caregiving without consideration to their relationship to the ill relative. In order to more effectively address this interest, future research must attempt to include a broader range of categories of kin including aunts, uncles, cousins, grandchildren and others.

As suggested earlier, much of the work completed by researchers, to date, has examined single variables and their effect on patterns of caregiving. It became evident in this study that several factors impact the involvement of provision of secondary care including characteristics of kin family members as well

as those of the ill relative and primary caregiver. Complex relationships and interactions appear to be operating amongst these variables and the nature of these interactions remain unclear. In order to evaluate the efficacy of family caregiving all components must be addressed including characteristics of the ill relative, primary caregiver and kin family members in addition to level and type of involvement provided. Future research needs to examine these variables simultaneously to determine who becomes involved in the process of care to the frail elderly.

VIII. Implications and Future Directions

The results of this study have implications for both theory and practice. With regard to theory, the findings of this research support the importance of gender in explaining family caregiving.

Findings from the present study suggest that the hierarchy of obligation for selection of kin family members for provision of secondary care differs for spouse and adult child primary caregivers. Age and gender of ill relatives and primary caregivers appear to be critical to understanding who becomes involved in caregiving to relatives with AD. Therefore, future research should address simultaneously the effects of the characteristics of the ill relative, primary caregiver and kin family member on involvement in order to further our understanding of family caregiving.

Findings from this study enhance our fragmented understanding of caregiving families of relatives with Alzheimer's disease. This study provided information regarding the size and composition of the kin and caregiving family. It also challenged the assumption that the kin family and caregiving family are synonymous. This finding has implications at the level of both policy and practice. Both policy makers and practitioners need to recognize the distinction between the kin family and caregiving family and acknowledge that because family members are present, they may not necessarily be involved.

Another strength of the present research is its focus not only on helping kin family members but also potential caregivers. Dwyer and Coward (1991) argued that all potential caregivers must be taken into account if we are to understand the role of gender in determining who provides care. Given that the present study focused on the caregiving family which is comprised of potential and actual helpers, the finding that women were more involved than men is strengthened. Finally, the present research provided a beginning picture of the relationship between a series of characteristics of kin family members and involvement in provision of care. Most importantly, information was discovered as to who is most likely and least likely to become members of the caregiving family.

Together, this information could be utilized by policy makers and practitioners to enhance their understanding of the composition of caregiving

families. A more comprehensive understanding of family caregiving, especially the determinants of involvement, will facilitate identifying primary caregivers who are at risk to provide care alone. In particular, information gathered from a primary caregiver regarding his or her kin family could be used to complete a risk assessment to determine if the primary caregiver is at risk of providing care alone. Practitioners must attend not only to those who are helping but also available helpers. They could also utilize the hierarchy of obligation to assess the likelihood of available kin family members becoming involved in provision of care and then, direct their energy towards enlisting kin family members who are most likely to become involved in provision of secondary care. Ultimately, practitioners could employ this information to identify gaps in helping networks and work towards better meeting the needs of caregivers of relatives with Alzheimer's disease.

Table 1

Characteristics of AD Relatives and Primary Caregivers

	Spouse	Adult Child	Test of Significance
Number	50% (n=52)	50% (n=52)	
Gender of Ill Relative			
Male	69.2% (n=36)	17.3% (n=9)	28.56
Female	30.8% (n=16)	82.7% (n=43)	.00*
Age of Ill Relative			
Mean	73.7	78.1	3.34
Range	57.0-87.0	65.0-89.0	.001*
S.D.	7.2	6.1	
Gender of Primary Caregiver			
Male	30.8% (n=16)	5.8% (n=3)	10.88
Female	69.2% (n=36)	94.2% (n=49)	.00*
Age of Primary Caregiver			
Mean	69.9	46.0	-15.88
Range	55.0 - 87.0	31.0 - 68.0	.00*
S.D	7.3	8.1	
Relationship to Ill Relative			
Wife	69.2% (n=36)		104
Husband	30.8% (n=16)		.00*
Son		5.8% (n=3)	
Daughter		80.8% (n=42)	
Daughter-in-law		13.5% (n=7)	
Employment Status			
Employed	5.8% (n=3)	73.1% (n=38)	49.32
Not Employed	94.2% (n=49)	26.9% (n=14)	.00*

Table 2

Percentage of Kin Family Members Helping and Not Helping for Spouse and Adult Child Primary Caregivers

	Spouse	Adult Child	
Number	287	274	
Helping	64.8% (n=186)	63.9% (n=175)	n.s
Not Helping	35.2% (n=101)	36.1% (n=99)	

*Chi-square 0.054 DF1 p>0.05

Table 3

Percentage of Kin Family Members for Spouse and Adult Child Primary Caregivers

	Spouse	Adult Child	Test of Significance
Gender			
Male	42.5% (n=122)	60.9% (n=167)	19.08
Female	57.5% (n=165)	39.1% (n=107)	.00*
Age			
Mean	51.7 (n=287)	35.3 (n=272)	12.21
Range	19.0-92.0	1.0-75.0	.00*
SD	15.8	16.0	
Kinship Relationship			
Sons	26.5% (n=76)	22.6% (n=62)	56.26
Daughters	30.3% (n=87)	20.1% (n=55)	.00*
Sisters	27.2% (n=78)	18.6% (n=51)	
Brothers	16.0% (n=46)	24.8% (n=68)	
Spouse		13.9% (n=38)	
Marital Status			
Married	72.1% (n=207)	49.6% (n=117)	27.94
Not married	27.9% (n=80)	50.4% (n=119)	.00*
Geographic Proximity			
Same household	2.4% (n=7)	27.5% (n=65)	72.55
Within 50 miles	44.9% (n=126)	30.9% (n=73)	.00*
Within Alberta	22.0% (n=63)	14.0% (n=33)	
Outside Alberta	22.7% (n=65)	22.9% (n=54)	
Outside Canada	8.7% (n=25)	4.7% (n=11)	

Table 4
Percentage of Kin Family Members Providing Help

	Spouse	Adult Child	Test of Significance
Gender			
Male	39.8% (n=78)	61.3% (n=119)	18.10
Female	60.2% (n=118)	38.7% (n=75)	.00*
Age			
Mean	46.0	34.8	7.62
Range	19.0	1.0-75.0	.00*
SD	13.7	15.1	
Kinship Relationship			
Sons	34.7% (n=68)	25.8% (n=50)	66.56
Daughters	41.8% (n=82)	20.6% (n=40)	.00*
Sisters	18.5% (n=10)	17.0% (n=33)	
Brothers	5.1% (n=36)	17.5% (n=34)	
Spouse		19.1% (n=37)	
Marital Status			
Married	73.5% (n=144)	39.2% (n=76)	23.32
Not married	26.5% (n=52)	41.8% (n=81)	.00*
Missing		19.1% (n=37)	
Geographic Proximity			
Same Household	3.6% (n=7)	23.7% (n=46)	50.19
Within 50 miles	56.6% (n=111)	30.4% (n=59)	.00*
Within Alberta	17.9% (n=35)	9.3% (n=18)	
Outside Alberta	16.8% (n=33)	16.0% (n=31)	
Outside Canada	5.1% (n=10)	1.5% (n=3)	
Missing		19.1% (n=37)	

Appendix A
Family Tree
Spouse Caregivers

Siblings	Children	Grandchild
___A-D-M-G	___A-D-M-G	___A-D-G
___A-D-M-G		___A-D-G
___A-D-M-G	___A-D-M-G	___A-D-G
___A-D-M-G		
___A-D-M-G	___A-D-M-G	
___A-D-M-G		
___A-D-M-G	___A-D-M-G	
___A-D-M-G		___A-D-G
___A-D-M-G	___A-D-M-G	___A-D-G
___A-D-M-G		___A-D-G
_____A-G		
Caregiver		
_____A-G		
Siblings of spouse		
___A-D-M-G	___A-D-M-G	___A-D-G
___A-D-M-G		___A-D-G
___A-D-M-G	___A-D-M-G	___A-D-G
___A-D-M-G		
___A-D-M-G	___A-D-M-G	___A-D-G
___A-D-M-G		___A-D-G
___A-D-M-G	___A-D-M-G	___A-D-G
___A-D-M-G		
___A-D-M-G	___A-D-M-G	
___A-D-M-G		

KEY: A= age
D= distance living from caregiver
G= gender
M= marital status - presence of spouse

Appendix B - Family Tree
Adult Child Caregivers

Aunts/Uncles	Siblings	Children	Grandchildren
___A-D-G	___A-D-M-G	___A-D-M-G	___A-D-G
___A-D-G	___A-D-M-G		___A-D-G
___A-D-G	___A-D-M-G	___A-D-M-G	___A-D-G
___A-D-G	___A-D-M-G		___A-D-G
___A-D-G	___A-D-M-G	___A-D-M-G	___A-D-G
___A-D-G	___A-D-M-G		___A-D-G
___A-D-G	___A-D-M-G	___A-D-M-G	___A-D-G
___A-D-G	___A-D-M-G		___A-D-G
___A-D-G	___A-D-M-G	___A-D-M-G	___A-D-G
___A-D-G	___A-D-M-G		___A-D-G
___A-G	___A-G		
(Mother of caregiver)	(Caregiver)		
___A-G	___A-G		
(Father of Caregiver)	(Spouse of Caregiver)		
___A-D-G	___A-D-M-G	___A-D-M-G	___A-D-G
___A-D-G	___A-D-M-G		___A-D-G
___A-D-G	___A-D-M-G	___A-D-M-G	___A-D-G
___A-D-G	___A-D-M-G		___A-D-G
___A-D-G	___A-D-M-G	___A-D-M-G	___A-D-G
___A-D-G	___A-D-M-G		___A-D-G
___A-D-G	___A-D-M-G	___A-D-M-G	___A-D-G
___A-D-G	___A-D-M-G		___A-D-G
___A-D-G	___A-D-M-G	___A-D-M-G	___A-D-G
___A-D-G	___A-D-M-G		___A-D-G

Key: A= age
D= distance from caregiver
G= gender
M = marital status - presence of spouse

Appendix C

Help Provided by Family Members

Part A. Please indicate whether you receive each of the following types of help in caring for your relative from other family members by checking off either yes or no. If yes, please indicate this person's relation to you.

			Relationship (sister, mother, etc.)
1.	Arranging appointments	Yes ___ No ____	_____
2.	Providing respite care	Yes ___ No ____	_____
3.	Accompanying relative/ caregiver on outings	Yes ___ No ____	_____
4.	Providing domestic care	Yes ___ No ____	_____
5.	Providing physical care	Yes ___ No ____	_____
6.	Providing entertainment	Yes ___ No ____	_____
7.	Handling business/legal affairs	Yes ___ No ____	_____
8.	Providing financial assistance	Yes ___ No ____	_____

9. Visiting relative during temporary hospital stay Yes___ No____
_____

10. Providing transportation Yes___ No____
_____

11. Providing relative/ caregiver with place to stay Yes___ No____
_____

12. Lending or giving something other than money Yes___ No____
_____

13. Providing comfort through physical affection Yes___ No____
_____

Part B. Please indicate whether you receive each of the following types of **emotional** support in caring for your relative <u>from other family members</u> by checking off either yes or no. If yes, please indicate this person's relation to you.

			Relationship (brother, sister, etc).
1.	Advice/information/guidance	Yes___ No____	_____
2.	Present in a stressful situation	Yes___ No____	_____
3.	Reassuring you that you are OK just the way you are	Yes___ No____	_____
4.	Comforting you by showing physical affection	Yes___ No____	_____
5.	Listening to you talk about your private feelings	Yes___ No____	_____

6.	Telling you that they feel very close to you	Yes___No____	_____
7.	Joking and using humour to try cheer you up	Yes___No____	_____
8.	Expressing interest and concern in your well-being	Yes___No____	_____
9.	Going with you to see someone who helped you with a problem you were having	Yes___No____	_____
10.	Doing activities with you to help your mind off things	Yes___No____	_____
11.	Telling you how they felt in a situation that was similar to yours	Yes___No____	_____
12.	Others (specify)	Yes___No____	_____

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